

# The 1849 Collaborative “Data Commons” Project

Child Welfare Council  
Data Linkage and Information Sharing Committee

## PRESENTED BY:

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# A “Social Layer” for Data

***Objective: Facilitate communication & collaboration between stakeholders who use (or would like to use) data to improve health & wellbeing in CA.***

Desired outcomes:

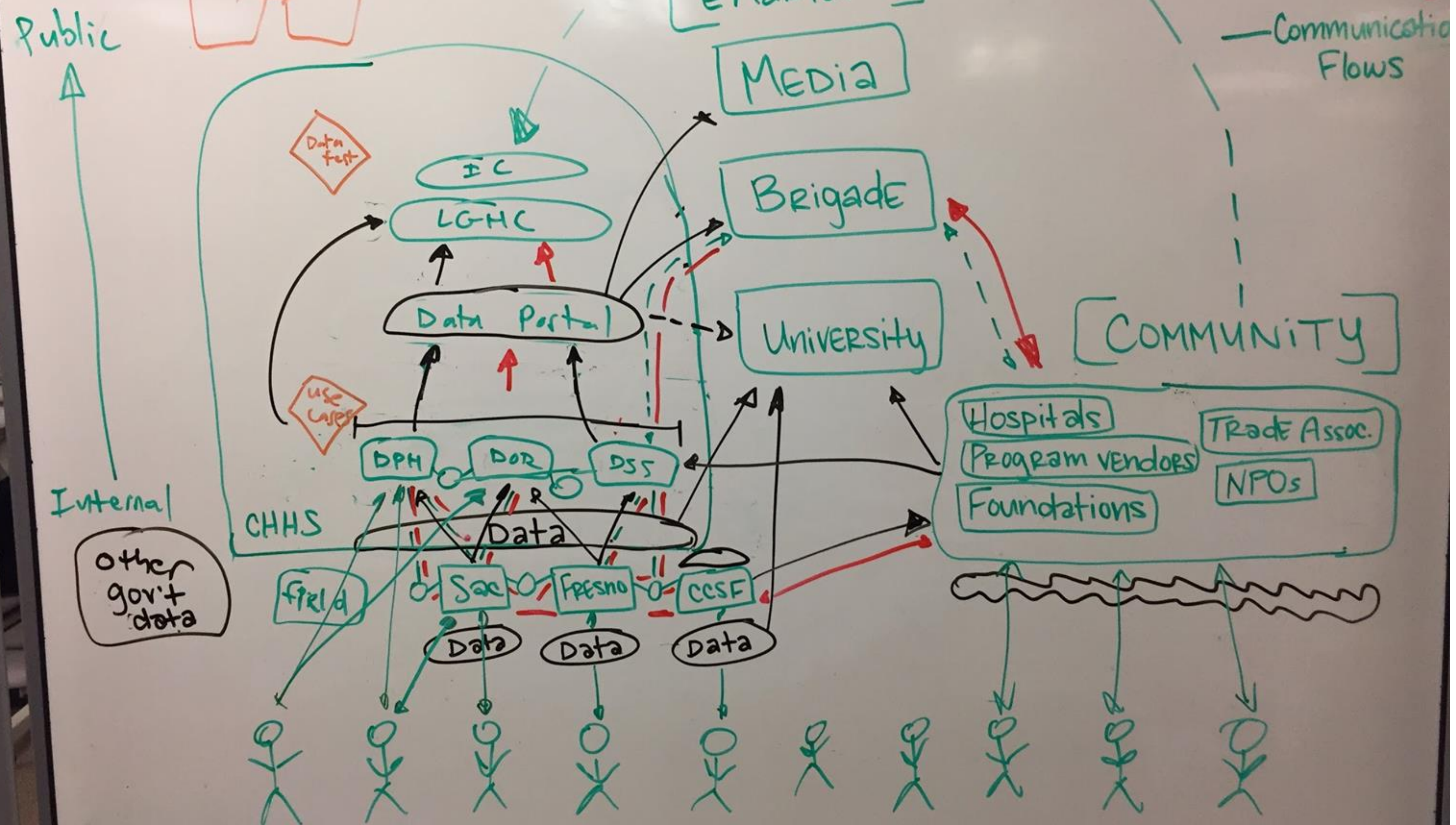
- Replicate successful models across the state
- Generate buy-in for new and innovative approaches
- Create cross-sector collaboration and engagement

Audiences / Users:

- CHHS staff
- County staff
- Data enablers – Civic Tech, media, researchers, etc.
- Community & service providers

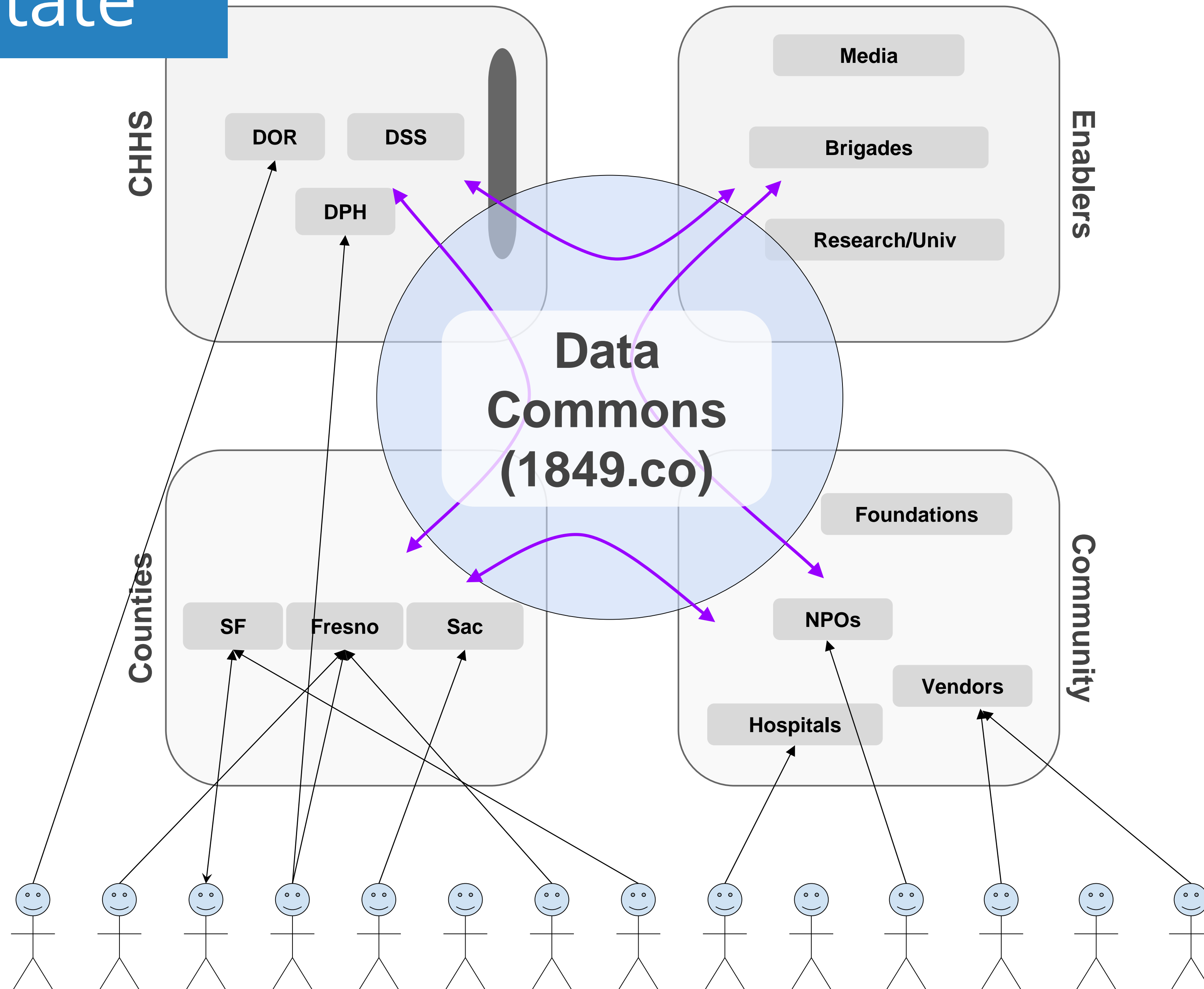


# Current State





# Future State





# Approach

Approach = User-Centered Design:

- Conducted 40+ interviews, 2 co-design sessions with users
- Agile development of prototype with regular feedback points with users

User “Personas” for Data:

1. The True-Believer
2. The Dutiful Doer
3. The Engaged Consumer
4. The Cautious Consumer
5. The Curious Advocate





# True Believer

**Occupation:** Chief Data Scientist or Chief Medical Information Officer

“I believe in the power of data, and I’m proud of my work, despite the challenges.”

The True Believer sees data as transformative, impactful, fulfilling and full of potential for delivering better government services. They seek out "data thinkers" and facilitate connections around solutions and knowledge-sharing through their personal networks. The True Believer is a point of contact for questions about data and as such, is motivated to break silos within departments and foster interdependent relationships.

## Needs

- Buy-in from leadership/political will
- Forum to share with professional network versus public
- Community of practice for storytelling and content curation
- Engagement with the data visualization community

## Opportunities

- Find examples of innovation work from peers, partners and community to generate buy-in with leadership
- Ask for help with initial proof of concept data analysis from civic tech community
- Publish shared best practices for government agencies to work with data

# Dutiful Doer

“Data is just part of my job.”

The Dutiful Doer's job often involves regular work with data, but has many other competing priorities that take up their time. "Dutiful Doers will reach out to policy / leadership (True Believer) types, or a point of contact to data producers or metadata owners to validate and understand data." They tend to share stories about their work with data in small teams or working groups, often in-person or through regular calls and presentations. Dutiful Doers are not typically concerned with interagency collaboration, putting the bulk of their focus on their own program.

## Occupation: Analyst or Program Manager

### Needs

- Incentives, increased bandwidth and/or external support for innovative work, collaboration and knowledge sharing
- Buy-in from leadership/political will
- Understand what users want and how they're using data
- Technical training and better tools for data work they are asked to do

### Opportunities

- Directory of resources such as toolkits, best practices and related Q/A forums
- Connect with community to extend capacity, such as co-exploratory data analysis work
- Gather input from community to understand their needs, what data they're using, and what's been built

# Engaged Consumer

*"Data is gold, but requires outreach and workarounds"*

The Engaged Consumer is passionate about data. They experiment with workarounds and learn new approaches to make data useful and tell stories or accomplish a task. If Engaged Consumers confront problems with data, they will often reach out to the data owners for further context or technical questions related to datasets and will go on to seek out content experts when questions can't be answered by data owners.

**Occupation: Brigade Captain, Data Storyteller, or Civic Tech Startup Developer**

## Needs

- Additional context to interpret data
- Consistent metadata and standards
- More granular data for deeper analysis
- More regular communication with data owners

## Opportunities

- Provide a direct channel to access content experts, and data owners
- Share stories that offer perspective on the context of data outside of the agencies that are producing it
- Publish and promote rules of engagement for optimal data standards



# Cautious Consumer

*"Data is valuable, but I have questions about the source, the quality, and how it is being used."*

Cautious Consumers spend time and resources on "cleaning up" data as opposed to reporting problems. They have a low tolerance for data challenges, and may have a skepticism around an agency's motivations for publishing open data, or an overall lack of interest in reaching out to data owners for more information or context. Sometimes this group works with data more as a hobby than part of their job.

**Occupation: Brigade Volunteer, Civic Tech Hobbyist, Journalist or Scientist**

## Needs

- Removal of barriers to use of complicated data
- Understanding of context / priorities of data owners
- Consistent metadata and standards
- More granular data for deeper analysis

## Opportunities

- Offer a channel for reporting data issues to establish communication and build trust
- Reach out to community for help with understanding context and ask for suggestions for other applicable data
- Provide background on why some data are only available internally and some are open

# Curious Advocate

*"I have a sense that data is powerful, but I'm not sure how to use it to answer questions about my community."*

The Curious Advocate believes data can help them but doesn't have the knowledge or tools to be sure. They are less likely to be technically-savvy and comfortable with large datasets and therefore are more likely to call or email agency staff as an attempt to get answers to specific questions about their community.

**Occupation: Community Organizer, Nonprofit Program Manager or Concerned Citizen**

## Needs

- Removal of barriers to use of complicated data
- Education, data literacy and tools
- Data visualizations that help draw insights
- A helping hand

## Opportunities

- Publish data in a visual and compelling way that relates to their direct community experiences
- Provide basic data literacy resources
- Offer examples of people to connect with to dig into data sets



# Product

## Current prototype:

- In closed beta
- Core feature = online forum
- Several active communities currently testing the platform:
  - Let's Get Healthy California
  - Local Health Data Managers and Epidemiologists (CCLHDME)
  - Code for Sacramento

## Future steps:

- Solicit more community participants, moderators/owners
- Integrate with additional data resources
- Consider how to add more features

***<https://1849.co>***

4 [Advancing Prevention in the 21st Century: Commitment to Action \(P21\) 2.0 Conference](#) Oct 15

[CCLHDME 2017 Annual Conference](#) Jun 13

[CCLHDME March 2017 Call](#) Mar 13





https://1849.co

### CDC Atlas Plus - Explore disease surveillance data

Data + Code

diseases-and-conditions

government\_data

data\_visualization

federal\_government

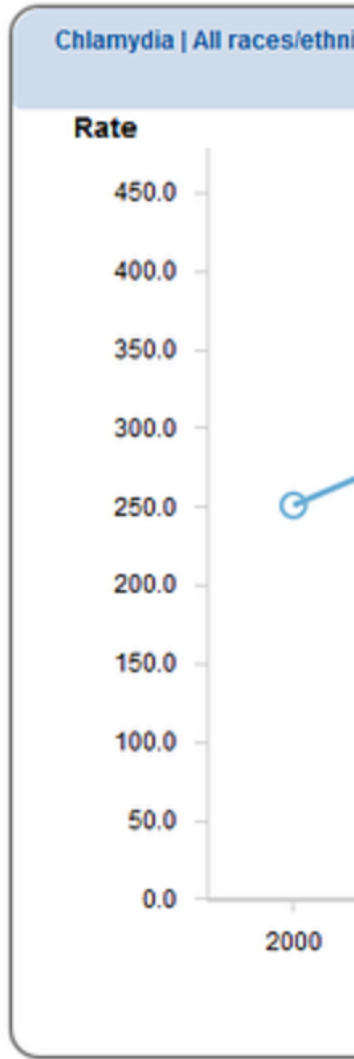
Michael.D.ValleCore Team

Jun 4

@MichaelSamuel , @rnapier , @ScottFujimoto , @Islone , @hdabritz , @jnagasako , @merryhh , @Tamara , @Scott\_Christman , @dauphine , @akrackov

Check out this data dashboard presented by the CDC. You can break down the data by disease and visualization type and compare rates by state. Very user-friendly experience. I wonder if this type of data presentation could be useful for Calif. region-specific data as well.

https://gis.cdc.gov/grasp/nchhstpatlas/main.html2



### HIMMS California State HIT Day 2017

Networks & EventsEventshithimsshealth\_itevents

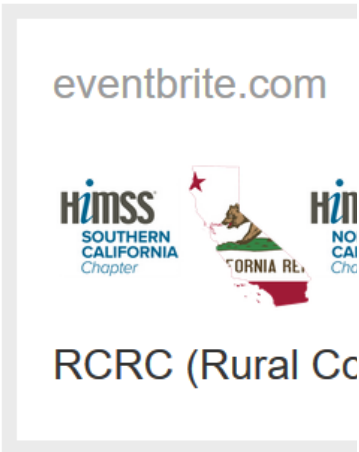
Michael.D.ValleCore Team

3Apr 30

The Northern Calif

May 3, 2017 in Sac

This is an annual o



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### CCLHDME 2017 Annual Conference

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7May 31

The CCLHDME Annual Conference was held on May 24, 2017 in Sacramento. The day was packed with dynamic presenters and topics relevant to this year's theme of Public Health 3.0. Presentations such as the Keynote by Dr. Baca, Senior Health Advisor for the Governor's Office of Planning and Research emphasized the importance of cross sector collaboration as look toward the future, focusing on health, equity and data. For more on the conference see the attached agenda and presentations below:

2017 CCLHDME Annual Conference Agenda.pdf5(374.5 KB)

\_Keynote \_Health Equity Data.pdf2(2.3 MB)

Building Epidemiology CapacitySMT.pdf4(2.2 MB)

California Burden of Disease and Cost Engine.pdf3(740.8 KB)

Coding for Mental Health and Drug Abuse in an ICD10 World.pdf(291.7 KB)

Electronic Case Reporting (eCR).pdf(534.0 KB)

Chronic HepC Surveillance\_What is Happening in California.pdf(843.1 KB)

Examining Access to Hospitals\_Physicians and Health Professionals.pdf2(921.6 KB)

Using CalREDIE to Strengthen Disease Surveillance.pdf1(476.0 KB)

Opioid benzo\_prescribing patterns\_fatal\_drug\_od.pdf1(715.8 KB)

Utilization of a Real Time Data Visualization Tool in a Health Services Clinic.pdf2(1.9 MB)

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R May 31	M Jun 13	replies	views	users	likes	links			